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## Independence at Risk: Older Californians with Disabilities Struggle to Remain at Home as Public Supports Shrink

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**SUMMARY:** This policy brief presents findings from a yearlong study that closely followed a small but typical set of older Californians with disabilities who depend on fragile arrangements of paid public programs and unpaid help to live safely and independently at home. Many of these older adults have physical and mental health needs that can rise or fall with little warning; most are struggling with increasing disability as they age. In spite of these challenges, most display resilience and fortitude,

and all share a common determination to maintain their independence at almost any cost. Declines in health status and other personal circumstances among aging Californians have been exacerbated by recent reductions in public support, and will be made even worse by significant additional cuts that are pending. Policy recommendations include consolidating long-term care programs and enhancing support for caregivers.

*“California’s LTSS network is fragmented and often uncoordinated.”*

**A**ging safely and independently at home is a strongly held desire among most Americans, and the U.S. Supreme Court’s *Olmstead* decision requires public programs to honor these desires when feasible. This policy brief reports on in-depth interviews conducted over a period of one year concerning 33 older adults who receive noninstitutional long-term care services and supports (LTSS). This policy brief documents the challenges experienced by this typical group of California seniors, who have been struggling with cuts to the state services they receive. Understanding the impact of LTSS on older people is particularly important given looming “trigger cuts” in these programs, which may occur if state revenues fall short of projections.

LTSS includes support services that address a range of care needs, including personal care, such as bathing; domestic tasks, such as meal preparation; and other assistance, such as transportation to medical appointments. These formal services often supplement and help sustain the informal care provided by family members, friends, and neighbors – the unpaid sources of support upon which many community-dwelling older adults rely.

Major LTSS programs include In-Home Supportive Services (IHSS), which pays for personal care assistance; Adult Day Health Care (ADHC), which provides therapeutic services for seniors and respite for their families; the Multipurpose Senior Services Program (MSSP), which provides enhanced case management and supplemental services; and nutrition programs, such as home-delivered meals.<sup>1</sup>



California's LTSS network is fragmented and often uncoordinated. The different programs have different points of entry and varied eligibility requirements. They are financed through different funding streams and administered through different departments, and they are not consistently available in all counties.

### **Needs of Low-Income Older Adults with Disabilities Are Unstable.**

The health and abilities of older adults receiving LTSS change continually, sometimes unpredictably. As a result, additional supports are not always in place when they are most needed. Although a few of the older adults interviewed experienced improvement over the course of the year, the most common pattern among respondents was a slow to moderate decline, and several people suffered catastrophic or other significant declines. The slow declines were difficult to identify in the short term, but they became more obvious over time.

Jill, a 72-year-old woman, was grappling with cognitive impairment and depression. Her situation is a good example of the continuous decline in health many seniors experience. She was living in subsidized senior housing and relying on the help provided by one IHSS caregiver. (To learn more about "Jill" and other individuals described throughout this policy brief, visit [www.healthpolicy.ucla.edu/HOMEstudy](http://www.healthpolicy.ucla.edu/HOMEstudy).) She described her changing health status:

*My brain has gotten worse and my body's gotten worse, and more than anything, I'm totally unpredictable. And, uh, in June I fell three times in a week. Once was on the way to the hospital, I fell, and so I walk like a snail now. I used to be a road runner, and (now) I walk really slowly.*

Among those with catastrophic changes was Michael, 74, who moved into a nursing home because of the day-to-day challenges he faced in managing his diabetes at home. Michael depended on one IHSS caregiver to provide assistance eight hours per day, five days a week. He was at increased risk in the evenings and on the weekends, when the caregiver was not around. As reported by Diane, his caregiver:

*He was having trouble reading his syringes. He had accidentally injected himself once with fast-acting that should have been long-acting. It was just getting messy, and he had a couple incidents in the middle of the night, and he was alone...on one occasion he called me, and on one occasion he called 911.*

Over the 12 months, several other study participants experienced major health events that resulted in emergency room visits and/or hospitalizations. These cases show that even within a particular trajectory, levels of need can rise or fall with little warning. A significant but not catastrophic decline is exemplified by the case of Margaret, age 79, who became blind as a result of diabetes. Assistance through both MSSP and special services for the blind kept Margaret's loss of vision from being catastrophic for her. She was provided with training and a wide range of talking devices (e.g., clock, phone, glucometer, and books on tape). These supports, along with personal care assistance, have made it possible for Margaret to continue living independently.

In a few cases, an older adult told of improvements in the recent past. In the case of Eileen, age 76, knee surgery and subsequent rehabilitation had significantly increased her mobility. Even with the surgery, however, she was limited to lifting no more than five pounds, so she continued to need some help with a wide range of domestic tasks and chores.

None of the low-income disabled older adults we followed had identical long-term service and support needs for the entire year, which created challenges for both the older adults

*“Levels of health need among seniors can rise or fall with little warning.”*

and their caregivers. When changes in their health increased their needs, some elders, like Margaret, were successful in obtaining additional help; others, like Michael, went without. Chronic mental health conditions, including mood disorders, were also relatively common in this group, causing many of the elders to be especially vulnerable emotionally as they faced an uncertain landscape of unstable personal health and uncertain support.

### **Most Older Adults with Disabilities Prefer to Remain at Home.**

One goal of home and community services is to allow older adults to remain safely in their homes.<sup>2</sup> For the majority of respondents, remaining in their own homes was the primary goal.<sup>3</sup> The desire for independence was well expressed by Roy, a 67-year-old man with neurological and psychiatric conditions:

*One of my greatest fears is being institutionalized... not being able to live independently and to be able to come and go... to be free, to have that freedom. I think those are ... very important aspects of life. Those are the things that give me a lot of joy and a lot of freedom.*

Independence for most older adults entails having a say in directing their care in a home setting. Vickie, 89, has been able to manage her care needs at home for the past several years. This has been made possible with the help of two dedicated IHSS caregivers who provide care to her in her home seven days a week. While Vickie's ability to stay at home is "supported" by the help she receives from her IHSS caregivers, a home health nurse, two social workers, and a Life Alert necklace, she perceives herself as independent and spoke of her wish to stay at home:

*I still want to be independent at this stage in my life. It's just so good to feel that you can still take care of yourself at 89 years old, because many people by that age can't do it at all.*

### **Even Those with Less Intensive Needs Rely on Supports to Get By.**

Some older adults with disabilities need around-the-clock care, while others manage with a limited number of personal care hours each week. IHSS provides a maximum of 283 hours of personal assistance services per month, so those with more intensive needs draw from other resources to piece together a network of care. Many use the IHSS hours to augment the unpaid care already provided by family members. Those who cannot turn to family members for assistance make other arrangements, including paying out of pocket, offering in-kind compensation in the form of personal valuables, or providing room and board in exchange for care services. For each IHSS consumer, the support provided responds to the individual's specific needs and helps avert or delay the use of more expensive care such as ERs, hospitals, and nursing homes.

Carmen is an example of a consumer with low-level needs and a sparse support network. At 65, she suffers from multiple conditions, including a congenital spine problem that has caused her chronic back pain for decades; hepatitis C; and several mental health conditions, including depression and anxiety. Her only source of assistance is the 40 hours of care she receives each month from her IHSS caregiver, who helps mainly with housework, laundry, and shopping. For Carmen, carrying groceries and laundry home is nearly impossible, as her rent-controlled apartment is a walk-up on the third floor. Carmen plans for the days that her IHSS caregiver is scheduled to arrive by prioritizing the tasks with which she needs the most assistance. With the caregiver's help, she is able to take care of her day-to-day needs as well as minimize her anxiety.

*“Seniors with intensive needs have to piece together an often tenuous network of care.”*

### Family Can Be the Key to Remaining Independent.

In California, family members can be paid caregivers under IHSS or can provide informal (unpaid) assistance, or both. The paid family caregivers among our respondents typically provided hours, intensity, and a feeling of care that exceeded their pay. Additionally, family and friends are often part of a complex web of support that maintains an elder in his/her home.

Even those with lots of family care can be dependent on public services. Miriam, who is 81, suffered a massive stroke and manages a host of chronic diseases that include diabetes, high blood pressure, and cardiovascular disease. She does not have use of her legs and has only minimal use of her arms; she uses a wheelchair for mobility and needs assistance from others with all of her personal care needs. She has been relying on an IHSS caregiver, a family IHSS caregiver, a full-time private caregiver, a wound care nurse, and the help of extended family members and other paid help for more than a decade. Initially, all six of her adult children agreed to provide financial support, hands-on care, or both. In recent months, however, the siblings' agreements have begun to unravel. One sibling lost her job, so another has increased the amount of care she provides:

*When my sister became unemployed, and then when her unemployment benefits ran out, we had to use my mom's surplus. Right now there's no surplus... cutting off that income put a financial deficit onto the family because none of us have an extra \$500 to give... It's really stressful at least half the time. I want to do it because my mom is my mom. Sometimes it's frustrating for me, because I just don't want to do it... but I've had to embrace the situation... She gave all those years to us growing up, and now it's our turn to give back.*

Miriam's case illustrates that however dense the network of care, it may still be quite fragile; particularly in these times of economic downturn, any disruption may jeopardize the

ability of an older adult with disabilities to continue to live safely at home. The support that LTSS provides for family caregivers is critical, given estimates that 88 percent of community-dwelling older adults with disabilities rely on family and other unpaid caregivers for assistance with their long-term care needs.<sup>4</sup>

### The Potential of Consumer Direction Needs to Be Optimized.

California's system of LTSS boasts the largest consumer-directed personal assistance program in the United States – IHSS.<sup>5</sup> IHSS allows consumers to hire, train, supervise, and, if necessary, fire personal assistance providers of their choosing, including family members. This program feature facilitates the ability of older adults to arrange care that is tailored to their needs and preferences and, in some cases, is more culturally appropriate.

Anne is one of Vickie's caregivers. She knows that being an IHSS provider is about more than just performing the daily tasks; it is also about the personalized touches that build the relationship between the consumer and caregiver and can lift the older person's spirits. Because Anne knows that Vickie enjoys looking her best, she assists by grooming her hair and painting her fingernails. She also helps Vickie take care of the flowers and plants on the balcony, since this is Vickie's main view from inside her small apartment. Anne explained:

*She has the balcony, you know... The flowers make her feel fresh, you know, happy, so that's why I help her water plants.*

These are the "side benefits" of care arrangements that, while not officially recognized, have profound and positive effects on older adults with disabilities. When consumers have a say in how to direct and use their assistance, they opt for those activities that provide them the most benefit. Promoting psychological health in this way contributes to physical health as well.

*“Paid family caregivers among our respondents typically provided hours, intensity, and a feeling of care that exceeded their pay.”*

Some older adults are very adept at directing and managing their own care. Roy is well connected to several formal services and organizations. He is an advocate for himself and knows how to pursue help until he gets results. He makes use of IHSS, MSSP, Meals on Wheels, and a variety of other aging and medical service providers. One factor that contributes to his dense network of formal support is his ability to seek help from organizations, even when his need may not be an exact match with the organization's services. For example, he successfully raised funds for an operation needed by his service dog after initially being denied help by several agencies. His persistence paid off. Roy is not hesitant to ask for help, and he sees his ability to be vocal as key to his well-being, since he does not have any family or close friends to advocate on his behalf.

Other older adults, however, have difficulty managing and maintaining a viable network of support; they may be less vocal than people like Roy and not as skilled at identifying available opportunities for engaging the support they need. Some are psychologically fragile in addition to being physically challenged. These individuals may want and need more care coordination, and the gaps in the system can become insurmountable barriers for them.

Fran felt she had nowhere to turn. She is 84 and has numerous health concerns, including diabetes, fibromyalgia, and osteoarthritis, as well as a history of a brain tumor. At the first interview, Fran was living in a home she owned; however, over the course of the study, she went through a foreclosure. Finding an affordable place to live was a source of great anxiety for Fran, since the waiting list for senior housing was overwhelmingly long. At the last interview, she was still searching for an affordable housing option. In addition to this imminent housing crisis, Fran has had difficulty retaining an IHSS worker who can assist her with getting out of the house, whether for medical appointments, shopping,

or social events. Over time, her inability to access transportation and other assistance has increased her social isolation. It has also worsened her depression, complicating her diabetes self-management.

### **The Availability and Scope of Public Supports Are Diminishing.**

Just as these older adults with disabilities experienced changing health over the 12-month period, the composition and sustainability of their support network also wavered. State cuts to funding and programs have weakened the infrastructure and reduced the scope of LTSS coverage in California. All of the older adults in this study experienced a 3.6% reduction in IHSS service hours as of February 1, 2011. While this is not a high number of hours for most consumers, it nevertheless contributes to the continued whittling away of the availability of hands-on assistance and other tangible supports for elders. Adult Day Health Care (ADHC) will be cut back in March 2012. To further complicate these changes, medical certification is now required to establish an individual's eligibility for IHSS, and funding for MSSP has been significantly reduced.

In addition to the direct effects on older adult consumers, family caregivers are also affected by state budget decisions. Some depend on ADHC as a source of respite and care for their older loved ones while they are at work. For Monique and her husband, ADHC provides essential respite hours, given that both work full-time jobs in addition to caring for Monique's mother, Yvette. Yvette, 78, requires constant care and attends ADHC five days a week. Monique spoke of their situation:

*My husband works in the nighttime and the evenings, so in the morning ... before I leave, he takes care {of my mother}, and then we're just waiting for the driver to take her to day care for three hours. That way my husband, he can get some sleep...It's just three hours, but at least it's something... it helps.*

*“State cuts to funding and programs have weakened the infrastructure and reduced the scope of long-term care coverage in California.”*



In addition to the core programs that provide direct services, such as IHSS, there is an array of financial, food, and housing assistance programs that also play key roles in keeping older adults living independently in the community. Several study participants experienced reductions in the amount of their monthly SSI/SSP check. Others experienced, or were anticipating, changes in their housing situation – due, for example, to foreclosure, eviction, or institutionalization. Such changes to their fundamental supports further compound the effects of the state budget decisions that impact older consumers of LTSS. With reduced monthly income, some seniors report cutting back on the amount of food they buy. Those at risk of losing their housing are encountering long waiting lists for subsidized housing and the accompanying real concern that no affordable housing options may be available.

*“If trigger cuts go into effect, the IHSS program is likely to see 20% across-the-board cuts in service hours.”*

Up to \$100 million in additional cuts to IHSS will be triggered by December 15 of this year if the Legislative Analyst’s Office forecasts revenues that fall below projections.<sup>6</sup> If this occurs, the IHSS program is likely to see 20% across-the-board cuts in service hours effective January 1, 2012.<sup>7</sup> Such a reduction in services will be certain to upset an already precarious situation for low-income older adults with disabilities who are trying to remain in their homes.

#### **Policy Recommendations**

With dwindling resources, it becomes even more important to strengthen the existing components of a supportive network of care for Californians with disabilities. Consolidating LTSS programs and enhancing supports for caregivers can improve the efficiency and efficacy of the current system of supports.

#### **Consolidate LTSS Programs**

The resources needed to coordinate a fragmented and shrinking system would be best spent on providing integrated services for seniors with disabilities. Other states have shown that global budgets for LTSS that cover all institutional and noninstitutional services provide more flexibility to offer the most effective care. Further, a single point of entry with a common eligibility and assessment process helps assure a more rational deployment of resources. The most comprehensive model, the national Program of All-Inclusive Care for the Elderly (PACE), pools Medi-Cal and Medicare funds. In this way, enhanced LTSS can be funded from the savings that accrue from keeping elders with disabilities healthy in their own homes and out of hospitals and nursing homes. When resources decline, this is the surest way to prioritize the care most needed by older adults with declining and often unstable LTSS needs.

The Affordable Care Act (ACA) provides a start. California is one of 15 states funded to design an integrated care program for individuals who are eligible for both Medicare and Medi-Cal.<sup>8</sup> This demonstration program allows four California counties to design innovative ways to coordinate primary, acute, behavioral, and long-term supports and services, with the goal of a statewide program.<sup>9</sup> The ACA also increases funding and expands the role of Aging and Disability Resource Centers (ADRCs). ADRCs provide information and assistance in planning for future long-term care needs and serve as a single entry point to multiple programs, but without any budgetary or administrative control over the disparate programs. A recent report ranked California forty-second nationally in ADRC functionality,<sup>10</sup> documenting that ADRCs could play a larger role in the state in connecting LTSS consumers to necessary supports. This is especially important for older adults with disabilities who are already managing an array of complex and chronic health conditions.

## Enhance Opportunities to Support Caregivers

A sustainable network of LTSS requires that caregivers be adequately supported. Recent studies suggest that California is not doing so well on this point. A recent statewide poll of California voters found that nearly half of those who identified themselves as family caregivers said they were not getting the social and emotional support they needed.<sup>11</sup> This finding is supported by a recent LTSS scorecard report that ranked California forty-sixth in the nation in the percentage of caregivers who are usually or always getting needed support.<sup>12</sup> The ACA includes a number of provisions that provide opportunities to enhance supports for caregivers by acknowledging their role as partners and decision makers in care delivery and by advancing efforts to better prepare them for their care tasks.<sup>13</sup> These are important steps toward increasing recognition of the essential role that family and other caregivers play in the provision of LTSS. The new provisions are a necessary starting point from which to build an infrastructure for caregiver support.

## Conclusion

The data from this study illustrate the full range of formal and informal supports that older adults with disabilities rely upon. Most of those interviewed over the past year do not know what to expect next regarding their own needs, and they cannot depend on the continuation of even the current level of supports and services they receive. As existing options for public support dwindle, it is uncertain whether these older adults, and especially those who are the least resilient, will be able to make do with even less.

## Methodology

The IHSS programs in Los Angeles, San Diego, Santa Clara, and San Francisco counties assisted us in recruiting 33 cases of adults age 65 and over who receive both Medicare and Medi-Cal and who depend on LTSS. All respondents had been subject to reductions in IHSS service hours, and many have had to adjust to reductions in other tangible supports, such as food or income assistance.

To the extent possible, we interviewed each older adult, her or his paid caregiver, and an unpaid family member four times over the period of a year. We followed a uniform set of topics but allowed the respondents to reply in their own words. Interviews were in English and Spanish, as needed; all were transcribed and coded by the research staff. The names and certain other identifying information (e.g., age and/or gender) have been changed to safeguard the confidentiality of study participants. For case studies of respondents, see <http://www.healthpolicy.ucla.edu/HOMEstudy>.

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## Endnotes

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- 2 The published mission of IHSS is to provide services “so that you can remain safely in your own home.” <http://www.dss.ca.gov/web/PG139.htm> While “safe” is not explicitly defined, we conceptualize it as involving an adequate level of care that is appropriate to the needs and desires of the older adult, with the risks of severe injury or complications of illness due to remaining at home not exceeding what a “reasonable person” in the same situation would find acceptable.
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